



# ASTHMA'S FUTURE IN UTAH: HOW WILL GENOMICS PLAY A ROLE?

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WORKPLAN

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## ASTHMA/GENOMIC PRIORITIES

Participants at the Asthma's future in Utah: How will genomics play a role? workshop held April 12, 2006, developed the priorities below. Additional discussion is found following the table. These priorities will also be included in the new 5-year Utah Asthma Plan, expected to be released May 2007.

### Pharmacogenomics

Strategy	Timeline
Develop "101" fact sheets on topics such as genetics vs. genomics, pharmacogenomics, direct-to-consumer marketing, genetic testing, asthma	July 2007
Develop a ½ day workshop for health care providers and/or participants of the workshop to provide updates on asthma genomics.	June 2007
Identify and recruit additional partners to assist with activities.	Ongoing

### Family History

Strategy	Timeline
Develop a public awareness campaign to educate on the importance of knowing your family health history.	July 2008
Provide education in organizational newsletters and listservs on family health history (why it's important, how to collect it, assessing risk, what to do after collecting it, and resources/tools available).	Ongoing
Identify family health history tools and resources currently available.	Ongoing

### Ethical, Legal, and Social Issues (ESLI)

Strategy	Timeline
Develop a survey for the general public to determine their beliefs and ideals about genetic/genomics issues. Based on the survey results, develop a plan to educate the general public and media (messages will include both negative and positive issues).	August 2007
Stay current in and watch for opportunities to participate in lobbying for legislation to protect against genetic discrimination.	Ongoing
Develop guidelines for companies on using genetic information (genetic discrimination, employment, insurance, etc).	July 2008
Review cases of genetic discrimination from other states to use in educational and legislation activities.	January 2008

# PHARMACOGENOMICS

## What do we still want to know?

- What gene(s) create a predisposition to asthma?
- Gene and environment interaction?
- How does environment affect the genomic challenge?
- How do we translate science into clinical application and who is responsible for doing this?
- Are we at the point that we can translate this? If no, what do we do know? For providers/patients?
- Understand the “pieces”/education for non-geneticists
- How do we focus limited resources?
- How do we apply this information?
- How is education being dispersed?
- Will insurance companies reimburse for genetic tests, even when the clinical utility is unclear?
- Who would make drugs for small genotype groups – what is the incentive?
- How will genotypes change behavior theory application?
- What will insurance companies do with the information?
- Will a physician have time to counsel patients?
- Have to know clinical interpretation for providers. How will physicians get new outcomes?
- We need to determine varying levels of “needed” understanding depending on audience (public, providers, public health, policymakers, researchers, etc).
- What is the cost of genetic testing?
- How is the testing done?
- How many providers are doing genetic testing for asthma?
- Based on the studies presented by GSK are providers aware of these results and are they testing patients?
- How does public health link with genomics? What is public health’s role?
- Who else is working on genomics issues?

## What are two things that could be done in the next year to integrate pharmacogenomics into asthma activities in Utah?

- Education – public, patients and their families, health care providers (nurses, respiratory therapists, pediatricians, etc), media, and legislators/policymakers
- Education – Activities:
  - “101” fact sheets (genetics, genomics, pharmacogenomics, direct-to-consumer marketing, genetic testing, asthma treatments based on genotypes, family history and risk assessment, etc)
  - Written materials
  - Round table – ½ to full day seminar for providers and clinicians
  - Increase provider awareness of the role of genetics response in drug trials (through conferences, CEU modules online, journals, etc)
  - Summarize what we know today and what it means for them
- Identify and recruit additional partners

- University level physicians (both to educate and participate in genetic studies)
- Outline expectations of the partners (brainstorm with each partner about contribution)
- 6 months – 1 year outline of partners and possible projects
- Recruit partners – start now 3-4 months
- Research
  - Create an information center (link helpful tools/practices for research)
  - Model Huntsman Cancer projects
  - Leverage currently existing databases: link genetic info with family information for research
  - Leveraging existing databases to transfer information for researchers, clinicians, etc
  - Develop databases and registries
- Streamlining HIPAA regulations to make information sharing easier

### **Who should be involved in this activity?**

- Health care providers (pharmacists, ER doctors, pediatricians, respiratory therapists, nurses, medical organizations, university programs, Intermountain Health Care)
- Asthma Taskforce members
- Pharmaceutical companies
- Researchers and clinical laboratories (ARUP)
- People with asthma and their families
- Insurance companies
- Genetic Science Learning Center
- Public health (epidemiologists, health educators, Utah Department of Health)
- Media
- Schools
- ALAU
- Software developers
- Legislators and policymakers

### **Priorities**

- Develop “101” fact sheets on topics such as genetics vs. genomics, pharmacogenomics, direct-to-consumer marketing, genetic testing, asthma treatments based on genotypes, family history and risk assessment, etc.
- Develop a 1/2 day workshop for health care providers and/or participants of the workshop to provide updates on asthma genomics.
- Identify and recruit additional partners to assist with activities.

# FAMILY HEALTH HISTORY

## What do we still want to know?

- What is currently being done in doctor's offices?
- Do doctor's use family health history in diagnostic?
- How to get health information to patients- how important is it?
- Insurance code for billable hours for physicians to address family health.
- Who gets genetic counseling and who pays for it?
- Is research aimed at prevention or cure?
- Is research being done to identify specific causes of asthma (i.e. RSV as a child as well as all other respiratory infections)?
- Validity of what is already being done (Sorenson Lab).
- Possible technological advances.
- What research has been done on the genotype & comment- slide- where did the information come from?
- What studies were referenced on this?
- What are the recommendations for taking a family history? From the asthma perspective? From researcher's perspective (asthma as part of history – documenting this and medications used)?
- How do we utilize the information we already have?
- Are family health history forms available online?
- How to use information obtained through family health history?
- Can family health history predict response to drug therapy?
- When is it more beneficial to use a genetic counselor VS. a family health history tool?
- What questions should we ask (specifically to asthma)?
- How to make an effective ad campaign?
- What the increase in asthma is due to? How much control do we have over our environment?

## What are two things that could be done in the next year to integrate family health history into asthma activities in Utah?

- Education
  - Public
    - Importance of family health history and options available
    - Promote knowing accurate family health history
    - Educating adults about mild signs and symptoms
    - Small public awareness campaign
    - Ad campaign to encourage gathering family health history information
    - Ad campaign to encourage parents with infants/toddlers exposed to 2<sup>nd</sup> hand smoke to be responsible smokers
    - Identification of other community organizations/ resources
    - Information sheets about family health history, asthma, etc.
    - Link websites with family health history information
    - Add family health history to Asthma Control Test (ACT)
    - Worksite emphasis

- How to: Directions- what do you do with the information?
- Health care providers
  - Information in newsletters
  - List of who is considered to be “Providers”
  - Develop family health history form to be used as patients check in or waiting for appointment.
  - ALA to sponsor asthma certification workshop (1.5 day training)
  - Resources for asthma education
  - Health Educators- require specialty certification in diabetes/asthma, etc
  - Provider education- circulate family health history questionnaire to be used in each practice.
  - Identify how providers use family health history information.
  - Recommendations on what to collect (How to: Directions- what do you do with the information?)
  - Documenting age of onset
  - Insurance (access to) may affect diagnosis
- Patients and their families
  - “Family Health History IQ” (FHH test or form for patient)
  - List of questions patients should ask provider
  - Include asthma information in health plan newsletters
  - Promote Open Airways and Camp Wyatt (asthma camp)
  - Policy changes
- Link current population to Utah Population Database
- What can be done to make information more readily available?
- Advocate funds for asthma programs
- Data collection
- Make health history on genealogy forms
- Possible Funding
- Incorporate tobacco programs into reaching asthma patients.

#### **Who should be involved in this activity?**

- Health care providers
  - Occupational health nurses
  - Intermountain Health Care (Select Health)
  - Intermountain Allergy (possible pilot test in these clinics, develop form to gather family health history information, education of triggers and asthma basics)
- Database through Primary Children’s Medical Center
- Patients
- Researchers (standardized, accessible, and coordinated)
- Legislators and policymakers
- Schools (promote resources already available, do an ad contest)
- University of Utah
- PTA
- Health Educators
- Utah Department of Health (genomics program)
- ALAU

- Utah State Division of Aging
- Faith-based organizations
- Genealogists/LDS Church (partnering to include family “health” history in genealogy records)
- Family Health History Task Force
- Public and Community based (grassroots) such as Latino organizations, civic groups, super markets
- Media

### **Priorities**

- Develop a public awareness campaign to educate on the importance of knowing your family health history.
- Provide education in organizational newsletters and listservs on family health history (why it’s important, how to collect it, assessing risk, what to do after collecting it, and resources/tools available).
- Identify family health history tools and resources currently available.

## ETHICAL, LEGAL, AND SOCIAL ISSUES (ELSI)

### What do we still want to know?

- How will information be used? How will we sort through information?
- How can we balance the needs and rights of all parties? (Insurance companies, employers, employees, consumers, etc.)
- What is being done to educate?
- Common perceptions of ethical issues surrounding genetics.
- How to ensure the privacy of genomic information?
- What will be done with the genetic information collected?
- Will we be able to alter a newborn's genetic coding with the genetic research we gain? What are some of the ethical issues?
- Will health insurance reform bring us to socialized medicine?
- How do we control health care costs?
- Decision making and accountability for insurance companies.
- More directly related to asthma?
- What do we do with the genetic information?
- Why is genetic testing treated differently than other tests of discrimination?
- Newborn screenings (Not DNA) – is it covered under the genetic discrimination law?
- Creating awareness is good – stimulates thought
- Potential paranoia about health conditions
- Pre-birth altering of DNA
- Where does DNA and other genetic information go? Where is it stored? How can the balance the needs and rights of both parties?
- Health Care costs/insurance Reform – Do we go to socialized medicine?

### What are two things that could be done in the next year to integrate ELSI into asthma activities in Utah?

- Education
  - Both positive and negative angles of genetic tests
  - Current policies and legislation
- Legislation
  - Support legislation
  - Watch and participate in policymaking process
  - Work on legislation to write off insurance premiums, and reduce percentage of cost ratio to earnings
  - Lobbying and legislation to change eligibility
- Develop ethical guidelines
- Explore ethical concerns – what do we do with the information?
- Case study reviews with asthma-specific situations

### Who should be involved in this activity?

- Media
- Researchers
- Health care providers



- Advocacy groups and the public (those with asthma and their families)
- Legislators/policy makers (Paul Ray – Utah House of Representatives)
- Utah Department of Health
- Federal and state governments
- University – review case scenarios
- Insurance companies

### **Priorities**

- Develop a survey for the general public to determine their beliefs and ideals about genetic/genomics issues. Based on the survey results, develop a plan to educate the general public and media (messages will include both negative and positive issues).
- Develop guidelines for companies on using genetic information (genetic discrimination, employment, insurance, etc).
- Stay current in and watch for opportunities to participate in lobbying for legislation to protect against genetic discrimination.
- Review cases of genetic discrimination from other states to use in educational and legislation activities.